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GENETIC DISCRIMINATION

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Looking Back to the Future?

by

Audrey D. Cole

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GENETIC DISCRIMINATION | Looking Back to the Future[1]

WHOSE FUTURE?

There is a growing perception that new sciences and technologies, and the findings of the Human Genome project in particular, could, in the future, provide an appropriate and cost-effective means of reducing the incidence of disability. This message, however, appears strident only to people who have personal knowledge and understanding of those of us who live with disabilities. For others, the message is hidden; only the potential good that could come from these developments is obvious. The "good" message is the one that we are most likely to pick up from the media and from those who have or may see themselves as having a professional or financial stake in the outcomes. Support for these emerging eugenics directions appears to have developed in the absence of clear and inclusive principles of justice, non-discrimination, respect for diversity and autonomy, and informed decision making. It has also developed without the input of those to whose very existence it poses the greatest threat.

But the future must be for all of us. The purpose of this paper is to reflect on how we can better understand our collective responsibility to people with intellectual disabilities and thus to humankind as a whole in the face of the genetic technology revolution. In doing that, I want to consider the perspective of the community living movement over the past 20 years, and the extent to which that perspective has become more deeply rooted in Canadian society, a society in which it seems that people with intellectual disabilities have always faced threats of one kind or another. I also want to reflect on whose values seem to matter, and which values should matter, in shaping our responsibilities to ensure dignity and human rights in the face of the risks that the genetic technology revolution poses. Finally, in reflecting on what has changed — or not as the case may be — over the past two decades, I want to consider what principles should guide our efforts to make sure that people with intellectual disabilities are not systematically harmed by the development and use of genetic screening and testing technologies.

LOOKING BACK

The 1982 CASHRA Conference, held at the Chateau Montebello, Quebec, included a session on Section 15 of the *Canadian Charter of Rights and Freedoms.* My role on the panel on that occasion was to talk about the implications of Section 15 for people with intellectual disabilities. At that time I was speaking as a member of the Canadian Association for Community Living (CACL).[2] For those who were not in attendance in 1982 (or who were but, "heaven forbid", have forgotten the gist of my comments), I feel obliged to refer back to my notes from that occasion. I do so not to boast about the prophetic prowess of the membership of CACL, but rather to reflect sadly on the limited effect we appear to have had in breaking down certain barriers to equality faced by people with intellectual disabilities, despite our collective efforts over the years. And here, I acknowledge the role that federal and provincial human rights commissions have played in those efforts.

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[1] This paper is based on a presentation by the author to the May 2001 annual conference of the Canadian Association of Statutory Human Rights Agencies (CASHRA) held in Whitehorse, Yukon.

[2] The Canadian Association for Community Living is a national voluntary federation advocating with and on behalf of people with intellectual disabilities and their families.

Members of CACL worked hard to get mental disability into the Charter as one of the prohibited grounds for discrimination. However, at the CASHRA Conference in 1982, I did express some personal distaste for a social climate that necessitated a labelling clause such as s.15 when people with disabilities, as human beings and as Canadian citizens, were surely protected equally by the generic Charter clauses. But we now know that, despite the Charter and the provisions in various human rights statutes across the country, we still continue to find ways to discriminate against people we devalue, often with significant success.

On that panel 19 years ago, I queried whether Section 15 would enable people such as my son, who was then almost 18 years old, to "go to school in his own neighbourhood with the kids next door, for the first time in his life." Although our son has always lived at home with his family, he is one of many people for whom inclusive education never did become a reality.

I also suggested that rights such as not being subjected to any cruel or unusual punishment were a travesty "for those people on whom we pass life sentences of incarceration for the social crime of being labelled 'mentally disabled.'" Nineteen years later, in Ontario alone, there are about 1,200 people still living in the three remaining provincial institutions. They are not necessarily people who have severe or complex disabilities. Many are older people who have yet to be given an opportunity to experience any other kind of life. Recent announcements indicated that the Ontario government was "thinking about" closing the remaining institutions. It is not clear to me whether those thoughts reflect the government's concern for the social well-being of the residents, or for its own ongoing effort to reduce government involvement in direct operation of services.

With Section 15 to bolster provisions already in the *Criminal Code*, I expressed the hope 19 years ago, that we would see prosecutions of people who withheld sustenance and allowed their newborn babies who had Down syndrome and a duodenal atresia to die. Would Section 15 mean that such people would be held accountable along with the practitioners from whom they had received the advice that led them to withhold consent for standard corrective treatment for duodenal atresia— surgery which, needless to say, was carried out routinely in the absence of Down syndrome?[3] We now know that such prosecutions are rare. Sadly, we cannot say the same about the deaths of human beings with intellectual disabilities either from this form of so- called "passive" euthanasia, or from other equally deliberate but more "active" forms of premeditated murder — the murder of Tracy Latimer by her father Robert Latimer is only one such example. I also spoke about parallel moral issues for which there would be no redress under Section 15, in particular the already growing practice then of prenatal screening and abortion of foetuses found to have Down syndrome or other detectable conditions such as spina bifida.

Finally, at that 1982 CASHRA conference, I expressed my belief that the practice of eugenics was once again alive and well in Canada. I also stated my fear that Section 15 would only be of benefit to my son and other Canadians were it to be used in conjunction with a collective social acceptance of moral accountability to fellow citizens who had disabilities — a social responsibility that I believe we inherently have for each other. It appears, though, that we continue to have difficulty with this notion in Canada today. In

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[3] In a 1974 paper, to which I referred at the time, (*Jnl of Paediatric Surgery* [December 1974]), surgeons reported that between 1950 and 1971 at the Toronto Hospital for Sick Children, 27 of the 50 infants born with duodenal atresia and Down syndrome were denied sustenance and allowed to die.

this paper, I want to articulate my understanding of what that social responsibility entails, and why I believe it is important that we act on it as the genetic technology revolution and its consequences loom over us.

WHERE DO WE BEGIN IN FORMULATING COLLECTIVE VALUES AND RESPONSIBILITY?

I have no training in law or in medicine, and my formal background in science extends no further than high school biology. But these are not the only places from which to begin formulating ethical principles to guide our actions. As in any consideration about life — and the use of genetic technologies is about nothing if it is not about life — we must begin with our own personal experiences of genetic technologies and what they mean to us in our daily lives. When I think about our responsibilities to one another, I work from the experience of spending 37 years in the company of a son who has a disability. This experience matters as we think about the future. Were my husband and I to have been 50 years younger than we are and only now at the beginning of those respective courses of events that finally brought us together in the early sixties, we might never have known the rewards of parenthood. Given the pressures of society in this harsh, materialistic world in which we now live, it is conceivable that, when the time would come, we would not be allowed to continue the pregnancy. We are thankful that our son was born in a time when it was not a social crime to have a child with Down syndrome.

We are not without values in which to ground our human rights commitments. But those values seem fragile in a world driven more by the push for economic development and globalization than by any sense of moral accountability to one another. This point struck home for me when I read a recent headline in a Toronto newspaper. It was coined from the last line of a short column reprinted from the *Schenectady Daily Gazette*, which read:

> *"But values, not just genes, are what makes us human."* [4]

That column was referring to the Human Genome Project. As some commentators have already noted, people are now being programmed to believe that we are utterly genetically determined and that nothing else matters." [5] One critic even suggests that "the laws of nature are being rewritten to conform with our latest manipulation of the natural world, allowing us to rationalize the new technological and economic activity of the Biotech Century as a mere reflection of the natural order of things." [6]

I think it is not simply my imagination that we are seeing more and welcome references to values in the media. Susan Swan, a professor at York University, was reported by one Canadian columnist as commenting that the spirit and values of "community" appear to be spread very thinly these days. She saw globalization as a culprit in pushing aside those fundamental values:

> *"... globalization is being used as an excuse to think of nothing but increasing productivity and profits. ... In society right now, it's all about getting a better price than the next guy in the electronic bazaar. The human spirit needs more than that. There's a need for an awareness that we aren't just automatons trying to meet the bottom lines.... Everything's so rapidly accelerated that there's a kind of radical discontinuity .... We don't really take time to look at the past and it's a treasury of wisdom."* [7]

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[4] "Values make us human, not genes." *Toronto Star*, 25 March 2001.

[5] Bryan Appleyard, "The Most Extraordinary Person I have Ever Known," *Sunday Times*, reprinted in *Toronto Star* (n.d.).

[6] Jeremy P. Rifkin. *The Biotech Century: Harnessing the Gene and Remaking the World* (Tarcher/Putnam (C), 1998).

[7] Jim Coyle, *Toronto Star*, 5 October 1999.

One of the gems in that treasury of wisdom has been there since 1866. Depositing it in the treasury was Samuel Gridley Howe, one of North America's best known pioneers in special education. For those unfamiliar with Howe's name, he is also credited with operating the first residential training institution in North America for people with intellectual disabilities. Opening a new facility for "the blind" in New York State, he said:

> *"Good intentions and kind impulses do not necessarily lead to wise and truly humane measure. ... Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half."*

"Meaning well and thinking right"! These are surely the values that most of us believe govern all our actions. I have absolutely no doubt that those who drive the juggernaut of globalization have convinced themselves that they are both meaning well and thinking right!

Even governments — of any persuasion — appear powerless to oppose the forces of globalization and are either willing to be, or resigned to being swept along by it. Today, the effects of globalized, corporate thinking are reaching into every aspect of human existence and, despite all the corporate reassurances of benefit, many people feel threatened by them. Nowhere is that threat more pronounced for people with disabilities than in the area of biotechnology. It is unlikely that there are many people with disabilities sitting around the board tables of the global corporate world. They are conspicuous only by their absence in the board rooms of biotechnology. Why are they not at the table? Why is it that the personal experiences of people with disabilities and their families appear not to matter as governments and the corporate sector alone frame the values that guide the genetic technology revolution? In order to understand why, we need to look at the assumptions about knowledge and science that, consciously or unconsciously, drive this revolution.

EUGENICS: THE OLD AND THE NEW

It seems, at the moment, that people with disabilities must struggle alone to find ways to stop others from inventing and practising a new science of eugenics — a science even more sinister than the so-called science of eugenics as we knew it in North America in the first half of the last century.[8] For, unlike the old eugenics, the new eugenics seeks not merely to denigrate, segregate, sterilize and otherwise marginalize on the basis of difference. Using the new tools of biotechnology, the new eugenics clearly seeks to destroy. In the old eugenics-driven period, only Nazi controlled Germany pursued its aim for a perfect race to the extent of destroying people with disabilities.

The "old" eugenics began to capture attention and gain public support in Europe and the American continent in the latter part of the 19th century. Its negative effects dominated the lives of people with intellectual disabilities in Canada throughout the first half of the 20th century. Vestiges of the attitudes and perceptions it generated continue to haunt

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[8] Wolf Wolfensberger, *Origins and Nature of Our Institutional Models* 1975 (1969).

[9] Although there is evidence that the notion of eugenics has been regarded by some people as advantageous to society since at least 600 BC, the term itself was coined by English scholar Sir Francis Galton. He first wrote about his notions of eugenics in 1865 in articles under the title of "Hereditary Talent and Genius," published in *Macmillan's Magazine*. In 1903, he defined eugenics as "the study of those agencies under social control, which may improve or impair the racial qualities of future generations, either physically or mentally." Galton, with a background in mathematics and medicine was a cousin of Charles Darwin. See Edgar Schuster, *Eugenics* (Collins, 1912). N.B. Between 1905 and 1907, Edgar Schuster held the first Research Fellowship in Eugenics established by Galton at London University.

people with intellectual disabilities to this day and to affect the quality of their lives and their status in society.

Since we find it difficult to see ourselves as anything other than caring and compassionate beings, I include a couple of examples from that sorry history. In the language of the times, a footnote from a Canadian professional journal in the period immediately after the First World War, illustrates the denigration of people with intellectual disabilities:

> *"Canada has a population of some 7,500,000, of whom, at a conservative estimate, some 40,000 are feeble-minded. When one considers that the number of Canadians killed in this war amounts to 55,000, the problem comes home forcibly. It means that there are 55,000 less of us to cope with this deficient 40,000. How is your community meeting the problem? Are "Simple Jim" and "Soft Maggie" and "Daft Joe" wandering around at their own sweet will? Do you know that from them and theirs, we recruit 60% of our prostitutes, 25% of our adult and 40% of our juvenile offenders?"* [10]

Statistical studies in heredity which had led to such crass and prejudicial statements were ultimately discredited as having been based on faulty premises, insupportable evidence and bad science. Nevertheless, the damage was done and the image of people with intellectual disabilities as inferior or less than human and as a social menace was planted firmly in the public mind, and particularly, in the minds of many practitioners of the disciplines of education, psychology and medicine.

A quotation from a 1963 medical text, the first edition of which had been published in 1908, provides the second example. Underlying this highly respected text one senses somewhat confusing values. Ironically, this 10th edition is dedicated "to all those persons of sound mind who are interested in the welfare of their less fortunate fellow creatures."[11]

The pros and cons of euthanasia are considered in the chapter on *The Prevention of Subnormality*. Here, it is suggested that "probably most people would agree that it would be better were there no defectives" but that did not mean that public opinion would condone "actively destroying them all." In justifying this presumption, Dr. Tredgold makes a distinction between "many high grade defectives" who could be seen as capable of "enjoying life, forming loving relationships with others, and of performing useful work..." and "many of the low-grade defectives" whose care and support "absorb a large amount of the time, energy, and money of the normal population." Appearing to argue for euthanasia for the latter group whilst acknowledging some of the difficulties it presents, the text continues, in language that seems unreal less than 40 years later:

> *"They cannot be employed to any advantage; moreover, many of them are utterly helpless, miserable, deformed, repulsive, unlovable and unloving ... Many clinicians believe that it would be an economical and humane procedure were their existence to be painlessly terminated, and that this would be welcomed by a large proportion of parents.*

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[10] *Social Welfare* 1 (December 1918): 65.

[11] R.F. Tredgold and K. Soddy, *Tredgold's Textbook of Mental Deficiency (Subnormality)*, 10th ed. (London: Balliere, Tindall and Cox, 1963).

[10] *Social Welfare* 1 (December 1918): 65.

[11] R.F. Tredgold and K. Soddy, *Tredgold's Textbook of Mental Deficiency (Subnormality)*, 10th ed. (London: Balliere, Tindall and Cox, 1963).

> *... The decision [to carry out euthanasia] is inherently difficult to make. In the case of monsters and profound idiots, few doctors will experience either difficulties or qualms, but with the next level of deficiency the baby will be some weeks old before a final decision can be made, and these are the cases that cause greatest hardship later. Every week the defective baby is allowed to live will make the decision more difficult.*
>
> *... In any case, euthanasia of the severely subnormal will do nothing to prevent a "defective" from being born. Can we suggest any measures to do so?"* [12]

The idea that criminality, promiscuity and other "social evils" could be attributed primarily to a supposed "class" of people that had a genetically inherited and limited level of intelligence is offensive to us today. Not only does it clash with our more progressive beliefs in human rights; it also seems inconceivable that with today's access to broader sources of knowledge and methods of communication we would simply believe what certain elite groups told us about such things. Nevertheless, these eugenic notions were the beliefs that prevailed during the lifetimes of many of our grandparents and great-grandparents of European and North American origin. They were firmly embedded in public policy. The suggested solutions to a perceived social problem were sterilization, segregation and euthanasia. In North America, two Canadian provinces and many if not most U.S. states had eugenic sterilization laws which applied to people with intellectual disabilities. Until the community living movement began to mobilize a little over 50 years ago, the policy and practice of segregation and institutionalization of people with intellectual disabilities in provincial jurisdictions and in most U.S. states was predominant and was considered appropriate by the populace. Only the notion of euthanasia caused the eugenicists to hesitate: was that because the "final step" was too steep" or, as Dr. Tredgold suggests, because euthanasia would do nothing to prevent the birth of someone with an intellectual disability?

The "new eugenics" are tailor-made to deal with Dr. Tredgold's problem — but, the "measures" it now appears to offer are not exactly new, at least for people with Down syndrome. It was about 30 years ago, when our son was 6 or 7 years old, that I first came across the notion of measuring the worthiness of people with Down syndrome in purely monetary terms. In an article about what he described as the economics of "mongolism", Terrance Swanson had this to say as he argued for the widespread establishment of genetic screening clinics and more liberal abortion laws:

> *"If 6,000 mongoloids live of the total that are born in the United States each year, we create a future commitment of $1_ billion per year ... Efforts to reduce the incidence of mongolism have the potential to be extremely cost-effective in terms of economic value and perhaps even more desirable in terms of other social values."* [13]

The federal government of Canada does not mention the cost savings related to eliminating Down syndrome or other conditions detectable in utero, as it pursues its own drive to foster increased biotech activity. Rather, the Canadian government speaks only of the enormous gains from new industrial activity and employment, and the enhanced national prestige that biotechnology offers.

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[12] Ibid., 469-70.

[13] Terrance E. Swanson, *Economics of Mongolism*, in *Annals*, ed. V. Apgar (New York: New York Academy of Sciences, 24 September 24 1970). For a Canadian cost-benefit analysis, see also, A.D. Sadovnik and P.A. Baird, "A Cost-Benefit Analysis of Prenatal Detection of Down Syndrome and Neural Tube Defects in older Mother," *Amer. Jnl. Med. Gen.* 10 (1981): 367-78.

Canada's Secretary of State (Science, Research and Development) recently announced the federal government's investment of $140 million in "Genome Canada."[14] In an eleven-paragraph statement, he spoke of Canada's position in genome research and the need to invest immediately or face erosion of that position; of Canada's need to be a leader in this effort and the government's concern that the United Kingdom, the United States and Germany were currently investing more than Canada in this research; and of Canada's need to be in a position to attract world class researchers to Canada. He said that the investment that Canada was making at that time would lay the groundwork for discoveries that would benefit "all Canadians." Almost hidden away in one sentence of the eleven paragraphs, was the statement that the "real benefits" for Canadians would be in terms of the "diseases cured and lives saved." There was, of course, no reference to the potential lives that would inevitably be destroyed.

So, with this focus, it should hardly strike us as strange that the federal government department with responsibility for Canada's biotech activity is Industry Canada with its focus on trade, corporate enterprise and profit!

Perhaps it is only to be expected that the recently established Canadian Biotechnology Advisory Committee — with the mandate to advise the federal government on biotech matters which include the Human Genome Project — appears to have no representation from the disability community. The government went to considerable publicized effort to invite nominations for this Committee from the disability community. They received nominations of people considered by disability organizations to be well-qualified, none of whom appear to have been appointed.[15]

It may be that people with disabilities have been officially designated at the world level as playing the social role of "sick person" rather than as decision maker in the global biotech stakes. At a recent meeting of the International Bioethics Committee of UNESCO, Diane Richler spoke as the representative of Inclusion International, and expressed the concern that this strong international advocacy organization had been included as one of a number of "patient associations" invited by the Committee to comment on the application of the principles of the *Universal Declaration on the Human Genome and Human Rights*.[16] But, as Diane Richler informed the Bioethics Committee, "disability is not an illness . ... Inclusion International and other international disability organizations have worked hard towards a redefinition of disability as a human rights issue".[17] Members of Inclusion International know that the day-to-day experience of people with disabilities dictates that disability be defined as a social rather than a medical issue. Similarly, here in Canada, members of CACL and other disability organizations have worked to that end. That was why we fought so hard and so long to get disability into the Charter and the various human rights statutes.

The Human Genome Project is here, presumably to stay, but certainly not to stay still! The initial mapping is now complete. That feat represents only "the end of the begin-

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[14] Honourable Dr. Gilbert Normand, "Genome Canada Announcement" (speaking notes for a presentation, Ottawa, 4 April 2001).

[15] Canada is not alone in failing to include people with disabilities in biotech decision making. A 1999 survey in the UK, *Genes are Us*, by the Royal Association for Disability and Rehabilitation, indicated widespread concern and fear that people with disabilities would be subject to new forms of discrimination and that the ethical environment in which biotech activity must take place, cannot be considered complete in the absence of input by people with disabilities. See "Gene genies: The opinions of disabled people are being ignored in the ethical debate over genetic testing," *Manchester Guardian*, 3 November 1999.

[16] Inclusion International is the federation of member associations in 115 countries representing 60 million people with an intellectual disability and their families. Diane Richler, the Executive Vice-President of the Canadian Association for Community Living at the time of writing, is President Elect and Secretary General of Inclusion International.

[17] Diane Richler (statement at the Seventh Session of the International Bioethics Committee (IBC) of UNESCO, Quito, Ecuador, 8 November 2000).

ning" according to one scientist, quoted recently. The beginning of "what"? That is the question for people with disabilities.

Catherine Frazee, a former chief of Ontario's Human Rights Commission, speaks with dignity and eloquence about the status and role of people with disabilities and has no illusions about the threat they now feel, nor of the different interests of the major stakeholders in the biotech race. On a panel I was privileged to share with her last year, she talked about seeing the stakeholders in the Human Genome Project as if in a family portrait, remembering that family portraits are always most interesting to those who are in them. In the biotech family portrait one can see the scientists, entrepreneurs, politicians, scholars, ethicists, lawyers, reporters, each discipline with its own particular stake, its own potential for gain, its own consequent interest in the outcomes, and its own presumed right to decide who should be sitting around the decision making table!

As I believe Catherine Frazee was suggesting at the time, given that the purposes of the Project and related biotech activity include the improvement of the quality of human life, finding cures for disease, and reversing unwanted human characteristics, who is to decide which human characteristics are unwanted? By which standards will quality of life be determined?

If UNESCO's International Bioethics Committee sees organizations such as Inclusion International as "patient organizations", what is the cure for intellectual disability? If the decision makers around the table have no experience of living with a disability, from what source do they rate the quality of the lives of such people?

Biotechnology may be relatively new, but the issues it raises now are rooted deeply in issues of discrimination against people with disabilities that have had a long and persistent history, predating even the "old" eugenics by many centuries. That discrimination relates to the fundamental question of whether disability is a fact of human experience and a natural element of human diversity, or whether it is a characteristic that can and should be eliminated from humankind.

In the course of the Human Genome Project, scientists have discovered and will continue to discover much about genetically-related conditions associated with disability. We cannot and should not want to stop scientists from doing scientific investigation — that's what science is about. We can and must have a say in what society does with the information.

We cannot stop scientists from discovering new ways to do things and new things that can be done to our bodies to change the effects of disease, or to protect our bodies from damage. We can and must have a say in what society does with this new knowledge and about who benefits (and conversely who loses) as a result of these new advances and technologies. We must have a say in shaping the underlying values and principles that will guide subsequent action. We must have more open discussion on these critical issues to ensure that the principles of justice, equality and respect for dignity and diversity apply to everyone. Genetic science promises to improve "everyone's" quality of life. The irony is that it also appears to promise the elimination of disability through genetic means. Does "everyone" not include people with disabilities?

Already we are hearing about the discriminatory consequences of failing to comply with pressures to undergo prenatal diagnosis and consequent abortion. In the United Kingdom, the Association of British Insurers has already adopted a policy that requires people taking out insurance to reveal the results of any genetic testing they may have undergone — although there is no requirement as yet to undergo such testing.[18] In other situations, people must now sign waivers on insurance saying that genetic testing has been offered but has been declined.

It is because of the persisting influences of both the old and the new eugenics that children with intellectual disabilities are still excluded from school; that they have been institutionalized and sterilized. As adults, they have been denied the opportunity to develop intimate relationships, to marry and to work. Typically, there has been little or no support for individuals or families. Today, in Canada, few families of adult sons, daughters or siblings still living at home have support that in any way matches needs. They remain on their own in a society that has literally turned its head and looked the other way.

RETHINKING PERSONHOOD AND DISABILITY

Why does the notion of eliminating disability sound like a good thing to society? We have to find better ways to help people to understand disability and to see people with disabilities as people, not as some clinical description of a syndrome or other condition.

What comes to mind when we think of physical disability? Pain? Discomfort? Unimaginable inconvenience? Have we consulted with people who actually live with such conditions or do we assume, like Robert Latimer presumably did, that a life that includes pain and discomfort is a life that no-one should have to live or that is not worth living? It is reported that over 70 per cent of Canadians believe that Robert Latimer should not have to serve his minimum mandatory sentence for the premeditated murder of his daughter, Tracy. Surely the calculated murder of one's child is an act that represents the most extreme betrayal of the trust any child should be able to place unconditionally in a parent. Do we imagine for one moment that Robert Latimer would be enjoying that public support had Tracy been able to say, "Please, don't hurt me, Daddy?" Do we imagine for one moment that this public support would be there had Robert Latimer murdered one of his non-disabled children on the basis of his own assessment of that child's pain or discomfort?

What do we think of when (or if) we think of intellectual disability? Inability to think, to reason, to make decisions? Incompetence? On the latter notion, perhaps we should heed the wisdom of the late Laurence J. Peter, author of the *Peter Principle*, who once said that competence, like truth, beauty and contact lenses, rests in the eye of the beholder!

What about the notion that disability is inherently a bad thing to have? People with disabilities don't seem to think so! According to whose values and by which standards would society determine whether disability is a bad thing? If people with disabilities are not at the discussion table, from whence comes the authority to make that determination? In an opening plenary address to the 2001 CASHRA Conference, Grand Chief Schultz made the point that for other people, that is people who were not of Canada's First Nations, to be advocating for retention of Canada's Indian Act was a clear violation of his rights.[19] For

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[18] "British life insurers set sights on genetic test results." *Toronto Star*. 19 February 1997.

[19] Grand Chief Ed Schultz of the Council of Yukon First Nations was a keynote speaker at the 2001 CASHRA Conference in Whitehorse.

other people to decide or even to advocate that disability be eliminated from the human experience is equally a violation of the rights of people who have disabilities, of all people who have disabilities. It also an affront to the human experience of natural diversity.

It would not be inappropriate to look to an eloquent and profound legal opinion on the matter of standards for making such judgements about life with a disability, pain or discomfort. For example, when Stephen Dawson was about 7 years old, he required surgery to repair a malfunctioning cerebral shunt that had been inserted soon after his birth and a diagnosis of hydrocephalus. He lived in a long-term care hospital. His parents refused consent for the corrective surgery, saying they preferred that he be allowed to "die with dignity" although no evidence suggested nor was there a likelihood of death.

In placing Stephen Dawson under the child welfare authorities to ensure his access to the necessary treatment, Mr Justice Lloyd MacKenzie stressed that irrespective of the disability, the presumption must be in favour of life and against the withholding of treatment. On the right and the appropriateness of others to make decisions on the quality of that life, he had this to say:

> *".... The presumption must be in favour of life. Neither could this court sanction the wilful withholding of surgical therapy where such withholding could result not necessarily in death but in a prolongation of life for an indeterminate time but in a more impoverished or more agonizing form.*
>
> *I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance.*
>
> *.... It is not appropriate for an external decision maker to apply his standards of what constitutes a livable life and exercise the right to impose death if that standard is not met in his estimation. The decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person - and in that context he would not compare his life with that of a person enjoying normal advantages. He would know nothing of a normal person's life having never experienced it."* [20]

The notion that we should even consider the elimination of disability by genetic screening comes from the arrogant presumption by those who do not have disabilities that people with disabilities live lives of little worth according to "our" standards of "what constitutes a liveable and worthy life."

Members of CACL and Inclusion International do not say that all genetic screening should stop. They do say that there should be no pressure on women to accept such procedures. There is concern about the sources of information provided to enable people to make "informed" choices. Upon the basis of what information is life with spina bifida or Down syndrome explained? Who is to advise potential parents or is there presumed to be some social standard of human acceptability? What values would underlie that advice? It is a fact that the majority of prospective mothers elect for prenatal diagnosis; if tests are positive for disability, most elect for termination of the pregnancy. Some reports have placed such election at over 90 per cent. Increasingly, such procedures are becoming routine treatment practice. As they do so, will there be any guarantee at all that women will

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[20] B.C. Supreme Court. *Re. S.D.*. 3 WWR 618. 1983. 629-30.

remain free to make a choice? One study already indicates that 40 per cent of referring physicians are of the belief that decisions about which foetal anomalies justify abortion should not even be made by parents but by the physicians themselves.[21]

As a parent of a son whose life in today's materialistic society is threatened by the direction and force of these new discoveries, knowledge and practices, I feel that I have something to say about the distinction between research to find means of ameliorating or otherwise lessening the effects of a particular genetic circumstance, and research which leads only to the destruction of the potential person who might be born with that condition. Let us not hide behind pretence but rather let us keep in mind that a full and complete range of prenatal therapies available to address all situations that might be detected is a long way off. Until then, prenatal diagnosis is purely and simply a tool of eugenics. It is a new eugenics, all wrapped up in complicated technology and elitist decision making, a process of unnatural selection which would weed out the unwanted under the delusion that it is both desirable and possible to ensure a perfect human race.

Already, genetic science has developed the means of producing "designer babies." A technique called PGD (pre-implantation genetic diagnosis) allows parents to reject unwanted embryos before they are implanted in the mother, thus avoiding the controversial implications of abortion. PGD is offered as an alternative when there has been a previous birth of a child with a condition such as Down syndrome.

Unnatural selection is not new. An earlier example, 20 years ago, was widely hailed at the time as an important "medical breakthrough." It consisted of "intracardiac puncture and ex-sanguination": in lay terms, the insertion of a needle into the heart of a foetus and withdrawal of the blood so that the foetus would die in utero. The reason for carrying out the procedure was to destroy one of twin foetuses so that the remaining foetus, which did not have Down syndrome, would continue to term. The reason for the application to court was protection from liability for those carrying out the procedure, should it inadvertently damage the foetus chosen to experience life.[22]

Is this the kind of world we want to live in? Apparently it is in the minds of some people. Some of you will remember a few years ago, reading about a discussion paper from a California chapter of MENSA, suggesting that it was time that society "face the concept that we kill off the old, the weak, the stupid and the inefficient ... [and that] those who are so mentally defective that they can't live in society, should, as soon as they are identified as defective, be humanely dispatched."[23] Who decides who can live in the community?

There is nothing intrinsically bad about disability. It enriches life, a fact to which my husband and I and many other people who have come to know our son can certainly attest. He is our only child. We have often wondered what kind of people we would now be had our son not been born. A world without disability could be a very sterile place in which to live. But more importantly, were we to eliminate genetically detectable disability in our society, how would we then respond to other kinds of disability? Tiny next steps take us into euthanasia for those we believe would be better off dead. Think about the 70 per cent of Canadians who already believe that Robert Latimer does not deserve the

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21 Michie et al. in Neil Sharpe, "Reinventing the Wheel??: Informed Consent and Genetic Testing for Breast Cancer, Cystic Fibrosis, And Huntington Disease," *Queen's Law Journal* 22 no. 2 (spring 1997): 389-452.

22 T.D. Kerenyi and U. Chitkara, "Selective Birth in Twin Pregnancy with Discordance for Down's Syndrome," *New England Jnl. Med.* (1981): 304.

23 Globe and Mail, *Mensa chapter sparks furore*, Jan 11, 1995. See also Toronto Star, *Mensa newsletter sparks outrage*, Jan 11, 1995

mandatory punishment for the murder of his daughter that he carefully planned and carried out. Who would be next? How would we redefine disability - what characteristics would take on that image? Which characteristics would be allowed? As Mr Justice Mackenzie said in the Stephen Dawson decision, quoted earlier, it doesn't lie within the prerogative of any of us to look upon another person and decide that the quality of his or her life is such as "not to be deserving of continuance."

I noted earlier that a shift forward in time could mean that our son would not have been allowed to be born. Had today's knowledge and technology been available in the social climate that fostered the old eugenics period, it is my belief that it would not have been necessary for Dr. Tredgold to note that euthanasia "would do nothing to prevent the birth" of people with severe intellectual disabilities or to seek suggestions of "measures to do so". Those "measures" would have been firmly in place. There has been progress since Dr Tredgold's words in 1963. Despite advances in public awareness and in legal and social mechanisms for the protection of human rights, however, it would be naive to think that the necessary mix of prejudice and public apathy to support such a social climate has dissipated entirely. Few people with disabilities, or their families and friends, could say that they have never been faced with either prejudice or apathy. Many families, known to me personally, have been painfully aware for many years that there are people in our society who question the right of our children to be here. The people who question that right undoubtedly think of themselves as caring and compassionate human beings, yet they have no qualms about expressing their disregard for certain people with disabilities even to those people themselves and their families.

My first rude awakening came a few weeks after our son's birth when I returned for the usual postnatal checkup. After the examination, the obstetrician proceeded to tell me how surprised he had been when he realized I had given birth to a "mongolian idiot"! Amongst the many things my husband and I had learned in the short time since our son's birth was the fact that the once common term "mongoloid" was believed to be no longer appropriate. The term "mongolian idiot" had surely been long gone from the language! It was profoundly shocking to me to learn in the subsequent conversation how little my obstetrician actually knew about people with Down syndrome. At that early stage in our own experience, I had no patience to sit there and teach him.

It was during the course of a long battle over the failure of the school system to serve our son that I had my second experience of the total ignorance of someone holding considerable public power and authority. Our son was about 9 years old. I was heavily involved with a group of parents in the area whose children were also excluded from the school system. Together with another parent, I was fortunate to find myself face to face with the Minister of Education in a doorway in the Ottawa Civic Centre in which the provincial cabinet was holding one of a series of town hall meetings.

I challenged the minister about the permissive rather than mandatory provisions in Ontario's Education Act of the time, provisions that allowed for the exclusion of children with severe disabilities from the local school system. The minister's response was immediate: "Surely, you don't expect the school boards to have to go into the business of building hospitals for the vegetables, or whatever you call them," he said. This time, I

was ready. I quickly replied that we called "them" our children and that we believed our children should have the same right as any other child in the province to go to school.

My family's third major encounter with this kind of ignorance in people who have had the opportunity to know better, was just a few short years ago. It is one that relates directly to genetic discrimination and was certainly the most painful of these encounters in our experience. My husband, son and I were at the graveside after the interment of my husband's oldest and closest friend. We were approached by the son of a contemporary of my husband and his deceased friend. My husband quietly introduced us to this man, a medical practitioner, who immediately asked our son's age. Although taken aback, I found myself telling him. "Ah!" he said, "just before amniocentesis!"

We were stunned! Somehow, the circumstances were just not right for the kind of response we should have made to this most blatant and cruel expression of disrespect for the humanity of people with disabilities and, particularly, of our son and us, his parents. I deeply regret that this man is free in his medical practice in the United States to advise pregnant women to do what he obviously assumed I would have done had the knowledge of and the opportunity for amniocentesis and subsequent abortion been available to me at the time.

I know that I should have told him of the gifts that Ian brought when he came into this world, and of the joy our son has given us and countless other people in the past 37 years. I should have told this man about love that is unconditional, knows no bounds and reaps unimaginable rewards. I should have told him of the privilege it has been to have been given the opportunity to be our son's parents. I should have told him of the dangers of allowing science and technology to develop in the absence of humility and an overriding concern for human dignity and respect. I will always be truly sorry that I failed to say those things.

It is attitudes like his that are relentlessly driving biotechnology towards a utilitarian society in which no-one will be allowed to have a disability because it will seem too costly to those who see themselves as taxpayers and sole producers of wealth and prosperity. Those are the attitudes that are leading us into a frightening world of totally unnatural selection in which humans, who found themselves on this earth not by any will of their own, will assume the morally indefensible authority to determine who shall share this world with them. That is not the world we want our son to have to face when we are no longer here to support him. We don't want to leave behind us a society that can't remember or recognize the value and contribution of disability to the richness and diversity of human existence. Many people with significant disabilities will be unable to tell the world that it is OK to have Down syndrome or spina bifida or any other disability and that there is much the rest of us can learn from them about life. Somehow, we have to get that message across to other people.

Victor Frankl, renowned as both a psychiatrist and a philosopher, was the only member of his family to survive the Nazi death camps. Reflecting on his experiences and his own struggle for survival, he wrote that it is essential to our human well-being that we always feel there is something significant yet to do.

WHAT ARE THE PRINCIPLES THAT SHOULD GUIDE US?

As we reflect on a world driven by corporate and technological interests, as we remember the messages of the community living movement during the past few decades, as we review the history of the eugenics movement — old and new — and as we question long-standing assumptions about personhood and disability, what principles might we adopt, what precepts might we hold dear to guide us in doing what needs to be done?

Some years ago, both CACL and the Roeher Institute contributed to an Inclusion International Issue Paper which identified principles that should underlie bioethical activities.[24] The principles of justice, non-discrimination, respect for diversity, and autonomy and informed decision making were identified. At the present time, CACL is developing particular statements of principle specific to the particular interests of the various stakeholders in the biotech revolution. Human experience reminds us constantly that no research is ever value free. In the absence of the values implicit in the principles of justice, non-discrimination, respect for diversity, autonomy and informed decision making, other values may detrimentally gain influence: the well-being and even the lives of people with disabilities will be further jeopardized.

These principles would ensure that people with disabilities or their chosen representatives be included in any bioethical policy decision; that no policy would lead to the devaluation or marginalization of people with disabilities; that technology never be allowed to define the meaning of life.

These principles are neither radical nor new. They are the fundamental democratic principles under which most citizens of Canada already believe they live. These same principles are implicit in our *Charter of Rights and Freedoms* and in federal and provincial human rights legislation. They are of the essence of a just society, the kind of society we want to believe we have in this country. It is in the interest of each and every one of us to make sure they are implemented.

A recent article appearing on the anniversary of the death of Pierre Trudeau, quotes a comment by Chad Garfield who directs the University of Ottawa's Institute of Canadian Studies. Irrespective of any political leanings one might have, Chad Garfield's reported comment about Pierre Trudeau contains a message that might help us in our task:

> *"Pierre Trudeau started to tell us that the challenges of the new era were not about economics, and not about politics - but about culture and civilization ... The events of Sept. 11 nailed that: The global issue now is about culture and civilization."* [25]

We cannot stand by and allow the genetic technology revolution and its consequences to be driven by global economic interests. Those consequences, whatever they may be, will shape our culture, our civilization, our human integrity and our future. That future must respect and include all people.

Yes, indeed, as Victor Frankl said, there is something of significance for us yet to do.

Audrey Cole is a long time volunteer in the Canadian Living and Human Rights Movements.

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[24] ILSMH in conjunction with CACL, *Just Technology? From Principles to Practice in Bioethical Issues* (Toronto, Ont.: L'Institut Roeher Institute, 1994).

[25] Graham Fraser, "Trudeau's legacy is still under assessment," *Toronto Star*, 28 September 2001.